DOCUMENT RESUME

ED 163 676 EC 112 446

AUTHOR	Teske, Jeanne Hughes
TITLE	Presentations for Parents, 1974-75.
INSTITUTION	Mountain-Plains Regional Center for Services to Deaf-Blind Children, Denver, Colo.
SPONS AGENCY	Bureau of Education for the Handicapped (DHEW/OE), Washington, D.C.
PUB DATE	Dec 75
NOTE	71p.
AVAILABLE FROM	Mountain-Plaines Regional Center for Services to Deaf-Blind Children, Colorado Education Department, 1346 Lincoln, Denver, Colorado 80203 ($2.50)
EDRS PRICE	MF-$0.83 HC-$3.50 Plus Postage.
DESCRIPTORS	Civil Rights; Communication (Thought Transfer); *Deaf Blind; Family Relationship; Health Insurance; Legislation; *Parent Workshops; Play Therapy; Recreational Activities; Severely Handicapped; Sex Education; Swimming
IDENTIFIERS	*Colorado Education Network for Resource Enrichment

ABSTRACT

All but one of the articles contained in the book were presented, either verbatim or in expanded form, at a series of Parent Workshops conducted by the Mountain Plains Regional Center for Services to Deaf-Blind Children. Titles and authors include "Parents Are People" (J. Teske), "Swimming Pool Activities for Deaf-Blind Children" (C. Stone), "Development of Gross Motor Activities for Ambulatory Deaf-Blind Children" (C. Stone), "Swimming Program for Deaf-Blind Children" (R. Lodi), "Influencing the State Legislature--A Success Story" (R. Horning), "Communicating in the Family" (V. Weiss), "Sex Education and the Multiply Handicapped Child" (H. Fischer), "Normal and Abnormal Reflexes and Their Influence on Motor Behavior" (B. Evans, L. Summers), "Your Child Grows and Develops Through Play" (S. Smith), "Legal Rights of the Handicapped" (S. Zimmerman), and "Health, Life and Hospital Insurance as it Relates to Families of Deaf-Blind Children" (J. Wigen). (DLS)

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PRESENTATIONS FOR PARENTS

1974-1975

Prepared by

Jeanne Hughes Teske,
Parent and Family Services

Mountain Plains Regional Center for
Services to Deaf-Blind Children

Regional Center Staff

John A. Ogden, Director
Dolores Mann
Terry Lee Smith
William J. Smith
Ann M. Stoddard
Jeanne H. Teske

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MPRC-DB-20, CDE 906
Presentations for Parents
80 + c., 1000 c.
March, 1976
No charge to Colorado Public Schools
Price $2.50

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This publication is funded by the BUREAU OF EDUCATION FOR THE HANDICAPPED, USOE, under Public Law 91-230, Title VI, Education of the Handicapped Act, Part C.

INTRODUCTION

During the 1974-75 program year, a series of single-state and two-state Parent Workshops were conducted throughout the Mountain Plains Region. Presentations on a range of subjects were made at these workshops. Some of the presentations appear in this publication exactly as they were delivered, and others appear in outline or summary form. The article by Robin Lodi was not a part of any workshop, but has been included to supplement the other material on swimming activities.

PRESENTATIONS FOR PARENTS

PARENTS ARE PEOPLE

by

Jeanne Teske, M.S.W.

Good Morning:

I am really pleased to be on hand for the first statewide parent conference for parents of deaf-blind children in Kansas. Over the past two years, I have seen about a dozen parent conferences take place in the Mountain Plains Region. Each of them has been fun to be a part of, and has laid the ground-work for exciting happenings to follow.

Various Kansas parents and professional people have been working up to this event over time, and several people, in particular, deserve a warm thank-you for their hard work in making it happen: Edna Bailey, Jean Hooper, Anita Peak, Harold Hodges, and Debbie Ikerd, who took on the role of chief organizer with lots of contagious enthusiasm. Also, the staff of the deaf-blind program here, who worked overtime when Debbie became ill last week.

Parent conferences such as this one provide an opportunity for you parents to pick up new and useful information that can be helpful to you in living with your handicapped child, since his learning is a more complicated process than it is for other children.

Parent conferences benefit more than just the children. They create an opportunity for parents and professionals to "let down their hair" a little and just be people together. The atmosphere is a lot more relaxed and casual than the usual settings where parents and teachers, aides or administrators meet each other. Take advantage of it to get acquainted and build a comfort with one another that will make working together for the children more effective from here on in.

There is another aspect of parent conferences that I want to mention. It is the most satisfying part of the experience for some parents. What I am talking about is the chance to talk and share with other parents whose children are similar to your own. You parents of deaf-blind children and your families face big challenges, hard decisions, a lot of frustrations and some very special triumphs with your handicapped children. Most of the time, the people nearest you in your home communities probably do not understand the intense feelings you experience. You must feel very alone and isolated at times like those. Today and tomorrow, you will have a chance to talk with each other about your similar experiences. That feeling of loneliness and isolation will lift for a while, because here is a group of people who do understand much of what you go through and who will have helpful hints and moral support to offer.

What I have been saying, is that parent conferences are a place to gain knowledge for your deaf-blind child, to meet comfortably with professionals and to reach out to other parents. Next, I am going to run down the conference agenda, so we can take a look at some of the specific things that will be happening, and get a sense for the two days as a unit before we get caught up in the separate parts of the whole.

The program today will give you a look at the three deaf-blind programs here in Kansas City, in Topeka, and in Wichita. You will have an opportunity to meet the staff of those programs, who will be glad to answer your questions. You will meet two people that I work with at the Regional Center. Lee Brooks will talk with you about how you can relate to the evaluation system that is being used in our region to help the programs in each state examine the job they are doing with children and make changes when the need arises. Ann Stoddard will think with you about habilitation plans for your child as he grows into adolescence and needs a suitable adult life plan.

After lunchtime, you will see a short, moving video tape. The star of the tape is a parent, a mother, who will talk very openly about the difficulties she and her family went through after the birth of her multi-handicapped son. She will talk, too, about how important it is to her to play a real part on the team of people who educate her son.

At the end of the day, you will hear from two other parents. Rosemary Horning will share with you her experiences in North Dakota, where she led the statewide group of parents of deaf-blind in pooling their resources and discovering what organized "parent power" can do for the children and their parents. Gary Cardiff, a father, will talk about parent groups on a larger scale. He is our region's representative on the Board of Directors of the newly chartered National Association for the Deaf-Blind. I think you will be excited by what is happening with these two groups. I am hopeful that it will stimulate you to form a group of your own, before the conference is over.

Tomorrow morning you will hear from another parent of a handicapped child. Luis Rovira is also a very knowledgable lawyer. He will discuss legal questions that are important for parents of special children to be informed about.

Throughout the whole conference, there will be valuable moments during coffee breaks, at meals, and between sessions to react to the content of the presentations and to simply visit. Most of us are pretty new to each other at this point, but by taking advantage of those spare minutes to get to know each other, as people, we will soon be feeling pretty familiar.

I have been talking so far, about the purposes of parent conferences, and the topics that will be covered in this one. Now, I will focus in on some issues that will feel a little more personal. These issues surfaced for me as I considered the thought-provoking title I was given for my talk to you today; "Parents are People". I will share them with you, as food for thought

and discussion in the context of this conference. In my thinking, they say something about how "Parents are People".

Parents are people in one very real sense. You have the special responsibility toward your child of communicating what it is to be "people" -- what it means to be a person. Sometimes we professionals (and you parents, too), who are working together for deaf-blind children come to think of you, their parents, as another type of professional member on the team that focuses on your child - the team that includes teachers, aides, social workers, psychologists, physical therapists, audiologists, program administrators, and so on. It is very appropriate that you be an active part of that team whose effectiveness is critical to the growth of your child and to your understanding of him. But it is important for all of us - parents as well as professionals - to remember that you are not simply another one of the disciplines on the team. We need to keep in mind the uniqueness of your role towards your child as a whole person - not as a narrow set of special skills. I would be willing to bet that you have not had years of special schooling to be a parent and did not receive a "parent diploma". You probably are not being paid a wage to parent your children. And you can not go home at the end of a hectic day, leaving your parenthood behind until the next workday. Your role towards your child is different: It goes on twenty-four hours a day, and the rewards do not come in cash. Your job is to follow your basic instincts - to love, care for and help your child the best way you know how. In the process, you teach him - or rather he learns - whether you intended it or not -- who you are as a person. He experiences you intimately - not only on your best behavior, but in your weak moments, too. Without really thinking about it, most of the time, you teach him how to become a person by your example, and how to recognize himself as a person in his own right. He experiences you as a warm body out there with strong feelings, as someone who is important to him and

to whom he learns to feel he is very important. He learns to accept your love and return it. If you are able to be together much of the time, he will just naturally learn the meaning of joy and sorrow, anger and pain from you. These emotions are an essential part of human life to everyone, and most children get a basic grasp on them from their parents.

Speaking of emotions, parents of deaf-blind children are people in another sense. As part of the experience of parenting a handicapped child you inevitably experience some scary, negative feelings: Sadness about the impairment your child lives with; anger about the way society sometimes reacts to him; and frustration about the difficulty of managing him at times. Your son or daughter may be one of the children whose feelings, toileting, sleeping, or medical needs presents insurmountable management problems in your home, for yourself and for your family, to the point where you are unable to keep him with you. If this is true, you have gone through a very painful separation in your family. You have probably felt a barrage of confusing emotions -- a feeling of loss, along with relief, of guilt along with the satisfaction that you have been courageous in making a difficult, necessary decision.

Parents are people who were typically husband and wife before they became parents. The demands of parenting a handicapped child can place a real strain on the marriage relationship. Sometimes wives feel desperately alone and burdened as the primary caretaker of the child. A husband may feel left out of the mother-child closeness and even rejected by his wife because she has so little time and energy left to devote to him. Husbands and wives have a need to share these feelings with each other. And they need very much to share the burden of parenting a special child. It is important to accept those negative feelings. After you have admitted those feelings to yourself and shared with your spouse or a friend, you will unlock more energy to focus on your child.

So, you parents are people in that you teach your children how to be persons, and you yourselves, experience a special set of intense, human feelings around the parenting of your handicapped child. Parents are also people in relationship to professionals. Professionals are more prone than anyone to forget to be people at times. They can get carried away with or locked up in their roles. You parents can be a tremendous help with that. You are the ones who know your child best and have the greatest investment in helping to shape his life. Share your goals for your child with his doctors and his teachers; tell them what problems and successes you experience with him outside the examination room and the school room doors. Insist on being a part of their planning for him, remembering that you hold a store of information about your child which they need in order to do their best job for him. If this kind of thing is new for you, it will come hard at first. But the results will be worth the effort. The moral support and the satisfaction that teachers, parents, and others can share in this way is great for everybody.

Your attendance here, for the conference, is a strong statement of your love and concern for your children. I hope you will jump right into things with both feet. Exchange ideas and experiences with each other and with the professionals. Feel free to share disappointments, criticisms and worries as well as the positive things. Soak up the information that will help you in living with your child and in planning for his future. Consider the possibility of forming a Kansas parent group. When you establish a parent group, you have a built-in system for continuing to communicate, share and work together.

In closing, I want to again encourage you to be yourselves. If you work at getting to know the other people here, some important goals of the conference will be achieved.

SWIMMING POOL ACTIVITIES FOR DEAF-BLIND CHILDREN

by Cynthia L. Stone, L.P.T.

Swimming as a recreational sport has many attributes for all children. The development of body image, muscular coordination and physical fitness are among these attributes.

In planning a swimming program for deaf-blind multi-impaired children, the program may expand beyond teaching the acquatic skill. An entire sequence of events involving language and socialization may easily be structured into the program. Self-help skills of dressing and undressing and bathing may be combined as a normal routine of events.

In-pool activities need not only include the basic preliminaries of adjustment to the water and learning the basic motor components to swimming, as floating, kicking with kick boards, and basic breathing patterns. Incorporation of basic language concepts of in, out, and under have a natural setting as the child will be able to associate meaning to his body movements. Basic concepts of empty, full, and buoyancy may be taught using such toys as large clorox bottles, whiffle balls and sponge balls.

Socialization activities can range from tying inner tubes together to form a soci-circle, to relay races with kick boards, to water gun play, to ball throwing and catching and to underwater treasure hunting.

By incorporating games into the swimming program, the children may be more apt to move and explore and enjoy the water. As with all other activities, the teacher must first meet the child where he is. The child must feel secure and relaxed and then he, himself, will generate the desire to move and play in the pool.

DEVELOPMENT OF GROSS MOTOR ACTIVITIES FOR AMBULATORY DEAF-BLIND CHILDREN

by Cynthia L. Stone, L.P.T.

Children learn about themselves and their environment around them through movement experiences.

The development of a movement repertoire is based upon two factors: central nervous system maturation and sensory-motor learning experiences within the environment. When either of these factors is affected - the child's movement repertoire will be impaired.

There are basically two stages in the development of movement experiences. The first year of life for the child is concerned with achieving the posture and locomotion ground work for independent standing and walking.

Through maturation of the nervous system and a myriad of sensory-motor experiences the child develops these basic motor components through constant repetition. He is learning how his body moves and how he can move through space.

What then happens to the deaf-blind child whose sensory receptors for vision and hearing are impaired, and many times also has central nervous system damage causing lack of development of the basic movement patterns needed for upright posture and locomotion?

Both channels for motor development have become impaired - he does not respond as the totally intact child does to his environment.

His world is distorted - he has difficulty learning about his body - that he has arms and legs that belong to him. His body does not function as a total unit but as fragmented segments. Instead of taking his shoes off with his hands he kicks them off with his feet. He is afraid of moving in the space around him and prefers to lay on his back and rock or flick his fingers in front of his eyes. He often rejects being touched or picked up as he has no idea what is out in his environment and he exhibits an almost primitive withdrawal reaction from the unknown.

He learns to walk much later than the normal child and his means of moving around are clumsy, almost robot-like. He has little concept of space around him and movement through it. Climbing, pushing, and exploring his environment with his body does not develop spontaneously as with the 18 month old baby.

His repertoire of body movements is unorganized and scattered and often has little purposeful meaning.

How can we organize his movement behavior and give it meaning, so that he can begin to relate to the environment around him?

A basic understanding of normal child development is necessary for tackling this problem.

A child's reaction to his environment from the day he is born is a motor response to sensory stimulation. These first motor responses are reflexive. A nipple is introduced to the baby's mouth and he reflexively begins sucking.

MOTOR BASE FOR LEARNING

These early motor responses soon develop meaning for the child long before he has acquired selective motor control. The baby sees his daddy cooing over his crib and his immediate reaction is to move his whole body in excitement.

The baby is reacting to a situation with a motor response which is not only mass movement but also has language and socialization implications.

Movement is never a separation from the child's social and emotional state. He is learning about his body and his environment around him and he uses his movement repertoire to give meaningful interaction to the environment.

The meaningful interaction of movement becomes more refined as the central nervous system matures and more environmental experiences occur.

BODY IMAGE - SPACIAL AWARENESS

Movement has meaning, movement patterns are developmental in nature and through movement the child learns first about his own body, then about how his body can move within his environment. He needs to learn that first his body can move and secondly there is environmental space for him to move in. The child is learning to perceive the world arourd him.

BASIC SKILLS

The normal child learns the basic skills of jumping, skipping, ball throwing, and galloping through play and socialization with his peers. He learns through imitation, motivation, and consistent repetition.

The deaf-blind child invariably is delayed in basic skill development - not only because of his distorted view of the world through his sensory impairments, but also because his play and socialization patterns are delayed.

Once again we see that we cannot look at the child's motor component without viewing him as a total person.

In planning gross motor activities for deaf-blind children we must take the three areas of Body Image, Environmental Space, and Basic Skills into consideration. We must see where the child is developmentally in all areas, we must find what movement has meaning for him, and we must structure his environment to give him the security needed for wanting to explore through movement experiences.

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SWIMMING PROGRAM FOR DEAF-BLIND CHILDREN

by Robin Lodi

All our children are non-swimmers, it is important that they all experience a sense of initial accomplishment in water activities -- for confidence and for a feel for the water. They must have trust in their instructor, knowing that their safety is assured at all times, and that they will be in shallow water (not over their head) until they are able to swim. Make the water fun -- not a dreaded activity. Unconsciously to the child, involve him in simple skills and games by which he will learn about adjustment, buoyancy, and body balance. This is a mental as well as a physical adjustment.

There is a learning sequence involved in beginning swimming: physical and mental adjustment, floating, gliding, gliding with kick, and finally coordinated stroking (higher skills are entries, personal safety, and rescue). One skill should be mastered before going on. Emphasize relaxation. Emphasize you do not stroke to stay afloat but stroke to move.

Learning Sequence

1. entering water
2. breath holding - face in water
3. mouth breathing in water
4. kick on front and back
5. prone float
6. back float
7. prone glide
8. back glide
9. prone glide with kick
10. back glide with kick
11. arm stroke on front
12. crawl stroke
13. arm stroke on back
14. back stroke
15. entries
16. personal safety

Robin Lodi

Swimming Activities -- Adjustment to Water

(do skills often for familiarity with water)

Objective: To assist child to overcome fear of water and to gain confidence in water.

Skills: Join hands and wade into water waist deep. Bob and rinse repeatedly to chin level. Gradually get wet all over.

Practice walking in chest deep water and in and out of water, first with instructor, then alone.

In shallow water lay on back or front, encourage face in water (and add kick after face goes in water).

Put toys on bottom for retrieval. Roll in water -- crawl along bottom, have walking, running races.

Objective: To assist the child to adjust his breathing to added pressure in water.

Skills: Take normal breath, close mouth, slowly lower head parallel to water.

Cup water in hands, wash and rinse face.

Exhale through mouth -- blow bubbles.

Jump up and down in chest deep water.

Count while underwater to increase length of time breath is held.

Rhythmic breathing --

Inhale through mouth as face is sideways resting on water surface with ear in water.

Rotate head to facedown position in water and exhale . . .

As head is rotated back to original position.

Bouyancy and Body Position

Objective: To assist child to relax while in a prone or back floating position.

Skills: Pick up objects from bottom in waist deep water, facing shore.

prone float: In knee deep water put hands on bottom for support, take breath, face down into water, lift hands from bottom and extend arms in front -- or do with instructor holding child's hands in extended position, child lowers hand into water and lies out on stomach with face down in water legs straight out.

back float — Instructor's hands under child's shoulder blades, child submerges to neck, lies back in water until ears are submerged, arms extended by sides, and feet extended.

Propulsion (glides)

Objective: To enable child to propel self in prone and suppine position.

Skills: Add a push to the beginning of prone float -- arms are extended, face goes down into water, push off bottom, glide without kick at first, later add flutter kick and increase length of glide. (Prone glide).

Submerge until shoulders are in water, lie back with chin tucked on chest, arms extended by sides, push from bottom (not too hard or water will wash over face). Do not bend body, or it will sink. After back glide is established, add kick to back glide. (Back glide).

BEFORE ADDING KICK TO GLIDES -- PRACTICE KICK SEPARATELY.

Kicks

Flutter kick — (on stomach) Alternate up and down action of whole leg. The movement originates at the hip, knee and ankle are relaxed, not bent -- they must be flexible. (Fins add flexibility, therefore effectiveness).

DO NOT OVERKICK!

Back kick — Alternate up and down action of whole leg, originating from hip. Emphasize pressing water up and back on upstroke. Ankles are relaxed and knee is slightly bent.

INFLUENCING THE STATE LEGISLATURE - A SUCCESS STORY

by Rose Mary Horning, Parent

By way of introduction, I would like to tell you a little about myself and my family. I am married to Henry Horning who is a cement plant foreman with a road contracting firm. We have three children, Colleen, age 15; Mark, age 13; and Jimmy, age 9. I am employed by the North Dakota State Department of Health in the Division of Health Statistics as a Nosologist and Computer Coordinator. I have worked with the Health Department for 12 years, with a 7-year break between 1960 and 1967.

Jimmy is our Rubella-syndrome child who has several uncorrected heart defects some central nervous system damage, profound deafness, total blindness, glaucoma, brittle diabetes and mouth-structure abnormality. Jimmy was at home until age 4 1/2 when it was necessary to institutionalize him to keep him alive, since his diabetes was uncontrollable for the most part.

On May 1, 1970, he was placed in our State School for Mentally Retarded, in the hospital section. Most doctors predicted he would never live to be age 5, however, today, at 9 years of age, he looks very healthy and is enjoying life. He learned to walk at age 8 as his light perception became dimmer and the light-gazing gave way to more activity. Jimmy especially loves the swimming pool, the trampoline and lots of attention. Sitting in a classroom is definitely not his bag, although he has made tremendous strides in that area.

North Dakota is a rectangular state which is about 375 miles from east to west, and 275 miles from north to south. We are definitely not square! Our Deaf-Blind Program was established at the Grafton State School for Mentally Retarded in the northeastern part of North Dakota near the Minnesota and Canadian borders. The

program became operative in March of 1972, after out-of-state facilities could no longer accept our North Dakota children into their programs. Since a few of the deaf-blind children had already been placed at the State School, the program was placed in that institution until a more suitable location could be obtained.

The unit for the deaf-blind was set up in a hospital ward where the children ate, slept, played and learned. Later classroom space was obtained in another building and the children became more active in other programs around the school.

North Dakota has 22 identified deaf-blind children. Our parents are scattered in all corners of the state and only three cities have more than one family. I live 300 milies from Grafton, so visiting Jimmy involves quite a journey. Of the 22 children, 15 are involved in the Grafton State School deaf-blind program; two children are in the School for the Blind at Grand Forks which is 40 miles south of Grafton, three children are involved in other programs because of a lesser degree of handicapping and three children are at home and are being assisted by Staff members from the deaf-blind program and by their local public health nurses.

In October, 1971, the staff at the Grafton State School held a three-day workshop to acquaint their people with the effects of the rubella syndrome and the type of children that are born as a result of maternal rubella. The parents of the identified deaf-blind children were invited to attend. In June, 1972, the Program Director and Ward Supervisor asked if I would accept the challenge of forming a parent group. Both of them had just returned from a workshop in Denver at which Mrs. Susan Mouchka of California spoke about the effects and purposes of such parent organizations.

At that time, I was a member of a Rubella Parent Group in the Los Angeles area and also belonged to the England Parents of Deaf-Blind Children. Through various means, I had already met four other North Dakota parents, so I had a base with which to begin my adventure. Mr. Syverson obtained permission from the parents to release their names, so I had a complete list of all identified children and their parents. The

State Health Department allowed me to use the copying machine to make our small number of newsletters I used to get our parent group organized. For the first few newsletters, I personally paid for the envelopes and postage, since I felt so strongly about the need for such a group. Later, parents began donating and, at the present time, most parents donate at least $5.00 twice a year.

In October, 1972, the staff of the Deaf-Blind Program organized a second workshop for parents which was well attended. The parents then decided they would like to meet twice a year, once in April and once in October. We have done so ever since. A form was sent to all parents asking their opinion of a newsletter, dues, etc., and because of the favorable results, we have continued our newsletter which we call "RUBELLA NEWS N' VIEWS".

The North Dakota law provides that parents of children who are residents of our State School for Mentally Retarded must pay a tuition which is currently $10.94 per day, until the child reaches age 18. Of this $10.94 per day which is changed as our economy changes, we as parents are charged from $10.00 to $100.00 per month, depending on our income, the amount of debts and the number of children we have. The remainder of the tuition accrues against the estate of the child and must be resolved when the child reaches age 18 or at the time of death, should that occur before the 18th birthday. At that time, we must either pay the balance or hire a lawyer to prove that we are unable to, at which time we must pay a minimum of $600.00.

In order to relieve parents of this tuition and provide fair treatment since our deaf children and our blind children receive a free education, the program people and administrators planned to move the deaf-blind program to our State School for the Blind which could also provide more space, better facilities and the use of many student volunteers from the nearby University. In order to move the program it was required that this must be done by legislative proceedings.

Rose Mary Horning

The North Dakota State Legislature meets every two years for 60 days in the odd numbered years. So, in January, 1973, several of us parents appeared before the House Appropriations Committee requesting that our children be moved to the Grand Forks School. Before the move was approved by the committee, they received calls and letters asking that the School for the Blind not accept our "retarded, diapered deaf-blind kids". Since most of the legislators themselves had never heard of a deaf-blind child, they decided it was best not to act on the situation at that time. As an alternative, the 1973 Legislative Assembly passed House Concurrent Resolution #3089 which required an interim study of the deaf-blind population and how North Dakota could best provide for these children.

The refusal to move our program in 1973 was actually a blessing in disguise. Because the parents had to work to attain something for their children, we became a close-knit and well-organized group. We had a goal to achieve, and with so few children in a population totalling around 650,000 we had no choice but to work together. During the two year interim, we met with the 12-member legislative group on several occasions. During one of the Committee Hearings, Doctor Edward Waterhouse, past superintendent of the Perkins School for the Blind in Watertown, Mass., and probably one of the most noted authorities on deaf-blind was invited to appear before this Committee. On one other occasion, each parent got up and spoke. Even if they only said two sentences, however, they made their wishes known to our state lawmakers.

At our workshop in October, 1974, we were already aware of several bills that would affect our kids in the January, 1975 beginning of Legislative Session. We already began preparing the parents for the need of having them drive to the Capitol City of Bismarck and appear before the various Committee Hearings.

The first bill to make its appearance was S.B. 2021 which authorized the Director of Institutions to place a deaf-blind child in any state program that was best suited to that child's need. Several parents attended that meeting and I testified in behalf of the Group. That bill passed both houses without any "no" votes. The Bill was sponsored by the interim study group.

The second and most important bill was S.B. 2007 which provided for state money to train and educate deaf-blind children within the State. Up to that time, the state provided $30,000 per biennium for out-of-state training for any deaf-blind child. This legislative session approved a good increase for the deaf-blind program along with the federal money that is provided. Many parents were present for that hearing and we made a tremendous impression on the Appropriations Committee when we nearly filled the hearing room. Bill Smith from the Regional Center came to help us along.

Four of us parents testified, having pre-planned our presentations so that we would not be repeating ourselves. I stressed the types of deaf-blind children that have been catagorized by Dr. Waterhouse, so that the Legislators would know that they may have to help support some of these children for a lifetime. Another mother used other states as examples and other types of children that were given education at state-expense, and stressed that it is a state's responsibility to provide education for its children, not the federal government's.

Several days after the Appropriations Hearing for the Deaf-Blind Program, the same Committee heard the budget for the Grafton State School. Since my child has been a resident of that school for 5 years, I also testified at that hearing. However, this time I used an entirely different approach. I got up before the podium and said, "Today I won't beg you for help, I just want to thank you for taking care of my child for the past 5 years. Because you provide a place for children such as my son, you have given him 5 years of life that was never anticipated." I left a copy of a newspaper article about Jimmy with the group and told them how he enjoyed the swimming pool and facilities that were provided at the State School. It was unbelievable

the attention and expressions on the faces of that group of Senators. I guess they did not expect a thank you. Sometimes we have to get to them through a back door. We found during the entire Legislative session, that by immediately writing them a thank you note when they voted in our favor, or writing and asking for an explanation when they voted other than we hoped, we kept their attention and kept them alert to our situation.

A bill that produced quite a stir among the parents of children at the State Institution was HB 1042, which would have placed the administration of the Grafton State School under the State Department of Health. At present time, it is under the Department of Institutions which also has the School for the Blind, the School for the Deaf, the State Penitentiary and our State Industrial School which is for teenagers with behavior problems. In meeting with the staff at the Grafton School, we learned that they were not in favor of being transferred and could not feel any justification in such a move nor could they see where the residents were going to profit. As parents, we were afraid that it would change the Superintendent of the School back to the medical profession which we had for 68 years. Our present Superintendent is a Doctor of Education and many good changes have come about since he began his administration in July, 1972. The proponents for the Bill were several legislators, a medical psychiatrist who also has a daughter at the State School, the North Dakota Mental Health Association which has 2,000 members, and the North Dakota Association of Retarded Citizens who claimed that they backed the move 100% (however, several of us who had children at the Grafton State School and are members of the ARC were never questioned as to how we felt.) One of our fathers raised the question during the testimony and that made a very favorable impression. Since I worked for the State Health Department, I was not allowed to speak, however, the night before the hearing, several parents along with our School Superintendent met at my house till 2:00 a.m. planning their strategy and

gave beautiful testimony. Following three days of hassling on the house floor, the Bill was killed and we all sighed with relief. We had 4 veteran legislators who testified against this bill and mentioned it was a political move without any regard for the children involved. I made sure to write them all thank you notes immediately after the hearing. One legislator wrote back and said my note "made his day". This bill's defeat was of prime importance with the deaf-blind program being located in two different institutions. With both being under the same administration, we can anticipate a good flexibility of moving students if need be.

Finally, the Senate introduced Bill 2262 which would eliminate the cost of care for residents at the State School. This Bill was killed before it ever left the Appropriation Committee since it meant a loss of money to the state in the sum of about $200,000 per biennium. The Legislators were also afraid that parents wouldn't have anything to worry about if we didn't have to pay the $10.94 per day for the education of our children. The House of Representatives introduced an identical bill, HB 1530, which passed the House by a vote of 87-11 without any problems. However, when it got back to that same Senate Committee that killed the first bill, it was really in a hassle.

That was a day I learned a few things about rough committee hearings. The same Senator who was instrumental in killing the first bill was really raking me over the coals, asking me what parents would have left to do if relieved of this responsibility, why we should be different than patients in our State Mental Hospital and a few other questions. Since I was the only parent present, it was up to me to get a point across to him. I told him that we were not without any worries when our children were at the State School, we still provided for their clothes, spending money, special medical needs, and the trips to and from the school were not free. We alone drove

almost 6000 miles during the year 1974. I also mentioned that our inmates in the State Penitentiary receive everything free, plus a college education, and most of them have wives and children on welfare. This same treatment is provided for the teenagers who spend time in the State Industrial School. The blind receive their education free, so do the deaf. I quoted the Amendment in the U.S. Constitution which states that every child, regardless of handicap is entitled to a free public education. This same right is repeated in the North Dakota Constitution. When I left the podium, this one Senator in particular said "I killed the first bill and I'll kill this one too." As soon as I got back to the office, I wrote him a very long letter in which I repeated many of the things I had said in the Hearing. I also sent him xerox copies of the U.S. Constitution and the North Dakota Constitution where it mentions this right, as well as 10 pages of lawsuits that were won by parents in other states and one in North Dakota when parents were required to pay for a child's education. The booklet I used is published by the Presidents Committee on Equal Rights for the Mentally Retarded and can be ordered. I also sent a very strong letter to five other key Senators along with the xerox copies of the information I just mentioned. We had some very good support on the Senate floor and, would you believe, the Bill passed the Senate by a vote of 46 yes and 2 no and 3 absent and not voting. The Senator who gave me the bad time wrote me a very nice letter and said that no letter received during the Legislative Session warmed his heart like the letter I had written to him and HE then carried the Bill for passage rather than indefinite postponement. He said it was because of my interest in that bill that it was passed. I cannot take the credit for that, because many of our parents wrote letters to their local Legislators when they could not attend hearings. Only two of us live in Bismarck and we took our vacation time whenever a bill was being heard, the other parents live from 100 to 300 miles from Bismarck and could not make all or many of the hearings, although two of our farmer families who live about 100 miles made it to almost every hearing, and that involved about 9 different sessions.

Rose Mary Horning

The phone calls I received at home from parents indicated that they were concerned and interested. I kept them all informed through letters as to the current status of the Bills in which we were involved and all parents had the numbers and committees pretty well memorized.

Yes, North Dakota Parents made a tremendous impact in our State Legislature this year. Although we have 22 deaf-blind children, about 8 families do not participate actively and we do not whether they do any letter writing or make contacts.

Our Parent Group has been fortunate in being so closely associated with the Superintendent of the State School for Mentally Retarded and the Superintendents of the School for the Deaf and the School for the Blind as well as the Director of Institutions and his staff. No other group of parents has this personal contact and can claim the friendship we have with these people.

Prior to July, 1974, North Dakota was under the Central Regional Center for Services to Deaf-Blind Children headquartering in St. Paul. Moving us under the Mountain Plains Regional Center, in Denver, Colorado, was the greatest thing that happened to us. We are still overwhelmed by the services this group provides and their willingness to assist us in any way they can. To Dr. John Ogden, Jeanne Teske, Bill Smith, Lee Brooks, Ann Stoddard, Terry Smith and Larry Slocum, a special thanks from the North Dakota Parents of Deaf-Blind Children. Within the next few days or so, we hope to become a chartered non-profit organization. We hope our story will help other parents in their Legislative endeavors and to achieve the closeness and friendship we have attained. Thank you!

COMMUNICATING IN THE FAMILY

by

Mrs. Viola W. Weiss, ACSW, BCSW

The family is the most enduring and the most universal of human institutions, probably because no other arrangement serves so well to meet the human needs of its members. Family life is different in different parts of the world and has changed a good deal here in our own country over the past few generations, but certain things remain constant.

The family, in all societies, is the principal source for the care and protection of children and for educating children into our own form of civilization. We civilize them by teaching them to use our language, by toilet training, eventually by indoctrinating them into our preferred set of religious or other ethical beliefs, as well as into our notion of good manners. But I think we do more; I think that within the family the child learns to be human. He learns to accept love and to give love. He begins to experience joy and sorrow, and anger and envy and pain and pleasure, all the human emotions without which, one could grow up to be a well-behaved, English-speaking robot.

These things are learned not through precept or any kind of formal training, but by growing up with adults who also experience these emotions and who have learned, through their own life experiences, to cope with the unhappy as well as the happy feelings.

From sisters and brothers the child learns to share. He comes to accept the fact that he is not really the center of the universe, that others have needs and

preferences and that parental love is big enough to go around to all the children.

And, of course, the family serves the needs of its grown-up members as well as those of the children. For one thing the family provides us with part of our sense of identity: we are the Smiths or Rileys or Weisses, or whoever. We are part of a unit that belongs to us and to which we belong, and this gives us a sense not only of who we are but also of attachments that are lifelong, perhaps the best antidote to loneliness and to alienation that one can have. For the grown-ups, exclusively, it also provides the highest degree of intimacy through the sexual relationship, which is also steady and continuing and a constant reflection of the fact that one is loved.

Within the family is also the place where one can most truly be himself. On the job, in the community, we may need to behave in ways which are to some extent prescribed by others; in the family we do not need to pretend. As a matter of fact, in the family we cannot really pretend. We all know each other well enough that moods or feelings are communicated without words. There is a kind of family radar by which we sense each other's emotions, whether spoken or not.

It is this sense of belonging and of sharing which makes it less difficult for us to face the stresses of family life, even the family tragedies. Having a very special child, a child with more than one physical problem, puts stress on all the family members. This kind of stress evokes many feelings in everyone in the family.

A family has a life history just as an individual does. And in each family there are what we might term developmental crises, occasions when families experience stress just because of the passage of time. Perhaps the first such developmental crisis is the birth of the first child. Husbands and wives need some time together in order to learn to live together, and when the first child comes, things

will never again be the same. No matter how wanted this child is, he makes things different. His being there creates some stresses. Other developmental crises occur when the last child starts school, and there are no longer any little children at home, when the children get into adolescence and prepare to leave home, causing parents to have all kinds of stressful feelings, and, of course, the last stress, when the children are really gone and the parents have to learn all over again how to be a couple alone.

The birth of a handicapped child presents more stresses than does the birth of a healthy child.* The mother, tied down with the constant care of a sick child, often feels resentful of the father's getting away from home to go to work, seeing his leaving each day as his being free of the burdens which she alone must bear. The father, for his part, may have difficulties on the job and on return home may have been expecting some expression of concern from his wife about his troubles, and he feels resentful if she is so concerned with the child that he may feel left out. One problem which can result from this set of circumstances is that privately each parent blames the other for his own feelings of resentment. This kind of problem can be the match that ignites a real blow-up between the two.

However, fighting is much better and basically healthier than the "silent treatment." This is almost always unproductive and makes the angry feelings last longer and could even make them chronic. Fighting usually leads to a making-up situation, which can be a reassuring thing for the once-angry parents as it will include some expressions of caring and of understanding.

* From this point on the material reflects the discussion and comments by the parents as well as the comments of the group leader.

Mrs. Viola W. Weiss

The best thing that parents can give each other is "moral support," that is, the knowledge that each understands the stresses the other is undergoing and that each is concerned for the pain the other is feeling. When there is this kind of relationship, the parents can be free to say to each other the things they cannot really tell anyone else.

One of these things is the thought that occurs to every parent of a severely handicapped child, that is, that things would be better if the child were not there. Parents sometimes are so horrified at themselves for thinking such a thing that they will not admit it to anyone. They seem to consider this the unforgivable sin. They feel guilty for even having the thought. Yet, all parents of such children do have it on occasion, and it is not a rejection of the child. Parents can be harder on themselves than anyone else is on them. It is important for parents to remember that they are people as well as parents, and that they have a right to some life of their own, both as couples and as individuals.

Parents of multi-handicapped children need to make the effort to insure that they have some time to be by themselves away from their children. And they need to have some time that is just for their own purposes, whatever those may be. No one else can prescribe this. It may be a night to go bowling. It may be just a half hour to sit in one's "private chair" where the family knows that no interruptions are allowed.

Grandparents can be a wonderful resource for comfort and for help in management, but they can also present problems to the parents and the children in the family. Sometimes for personal reasons of their own the grandparents may not be ready to accept the handicapped child and thus may withhold their affection and interest. Other times the grandparents may over-give to the handicapped child, or show him

attentions and give him presents which they do not do for the handicapped child's sisters and brothers. Each pair of parents must work out his own solution to these problems, even if it means that they keep more distance from the grandparents than they would really like to.

People outside the family can also add to family stress. The professional persons with whom the family must deal often seem unfeeling and unnecessarily brusk in their interpretations to the families. While the parents can understand that the diagnostic team which evaluates their child are specialists and see hundreds of children a week, it does not help when the specialists seem to be totally unaware that the parents have spoken to a half-dozen people in the same day, all of whom have been just as "brutally frank" as the others. Parents may even feel that the specialist is not giving an accurate evaluation of the child in that he may not be taking into account the fact that the family has traveled miles to get there and that the child is tired and not functioning as well as he can at home. Some parents have found that it is not necessary to hide their anger at these evaluators, or even worse to feel that somehow they are responsible for the child's difficulties and are to blame. It always seems more helpful to admit where the anger belongs, and, if possible, to express it at the place it was stimulated.

Thoughtless comments and questions by neighbors and sometimes utter strangers also can produce stress for the families of handicapped children. It is particularly frustrating and anger-producing when strangers talk about the child in his presence, as if he were a thing instead of a person. The child himself ultimately needs to be helped to handle this problem, since it may occur also when the parents are not present.

Humor can be a great aid to parents. It offers a means to turn their anger

into a form they can handle, and it provides release from the tensions these angers build up. It also produces a bond among parents of deaf-blind children which makes them feel together that they can cope with the inevitable stresses that they will face.

SEX EDUCATION AND THE MULTIPLY HANDICAPPED CHILD

Henry L. Fischer, Ph.D.

INTRODUCTION:

Much of the work that has been done in the area of sex education with the mentally retarded or developmentally disabled child has been done with children and adolescents who are not visually or auditorially handicapped. Workers in this area have been able to rely on vision and audition, on graphic materials and verbal labels. They have also been able to rely on the child's ability to express what he knows, to reflect on experiences or behavior and talk about them. The retarded child who is not severely handicapped in most instances can clearly relate to another human being and is able to describe feelings he has toward other people. The situation with the sensorially handicapped or multi-handicapped child is quite different.

In this paper, I would like to briefly outline a general technique and some basic philosophy relative to sexuality and the developmentally disabled individual and then make an effort to apply some of these comments and philosophies to work with the deaf-blind child around sexual development. The definition of sexuality to be used in this paper is a broad one, not being limited only to a discussion of body parts and body functions but rather including issues such as attitudes, sexual feelings, customs and other sexually related behaviors.

TECHNIQUE AND PHILOSOPHY:

In some earlier work with mentally retarded youngsters and their parents[1,2,3] the following technique was developed: initially, the interviewers met with the parents to discuss any concerns or problems the parent had in considering the child's growing sexuality. Following this interview, the parents were shown the visual materials and questions that would be presented to the retarded child. Next, the child was interviewed with the parents observing from behind a one-way mirror. Finally,

following the interview of the child, a feedback discussion was held with the parents to pick up any of his or her observations about the child's interview. This technique gave rise to a variety of parental attitudes and points of view. (1) Sexual development in the retarded child is given a lower priority than other concerns. Some parents feel that because they consider it less important than other physical or educational concerns, it can easily be put off until later. (2) Raising the issue of sexuality with it's description of body parts, words or behaviors can only arouse the child's curiosity and may lead him to into behavior which he otherwise might not think to get into. Therefore, discussion of sexuality should again be avoided for this reason. (3) There is the general feeling that the handicapped child will have a difficult time controlling his sexual impulses and feelings, as it is best not to discuss these with him. (4) A frequent consequence of this general avoidance of sexuality is that when masturbation and menstruation normally occur in the course of development, they are regarded as crisis situations. Typically the child has had little preparation and the whole situation is seen as a negative thing rather than as an opportunity for growth. (5) We had the frequent experience of seeing that the very fact of raising the issue of sexuality also raised for most parents the reality that their child is and will be a sexual being. It forced parents to grapple with ideas about what they felt their child would eventually be capable of. It raised important questions about dating, marriage, contraception, parenthood, sterilization, and the eventual living circumstances for their child.

In our on-going discussions with parents we have evolved some general principles that would appear to have relevance for all parents of handicapped children including the deaf-blind, multi-handicapped child. (1) It is important to acknowledge that even the handicapped child will have normal sexual urges and desires as far as we are able to determine. Handicapped children who are functioning at or above the level of

moderate mental retardation should certainly be assumed to have these interest and desires. (2) It is important for parents to examine their own beliefs and feelings about sexual behavior not only in general but for their particular child. The importance of knowing one's own reactions to discussions of sexuality is critical before one can be an effective teacher of others about sexuality. (3) It is important for parents to examine their anticipated goals for their child when that individual reaches late adolescence or early adulthood. By doing so one can take the necessary steps to prepare that child for reaching those anticipated goals. (4) Parents and teachers of the handicapped child need to recognize that this child will not develop appropriate sexual behaviors overnight or at the onset of menstruation, for example. The child must be taught about sexuality in the same way that he is taught about a variety of other things. (5) It is also important to recognize that children will readily pick up on the general atmosphere that exists in the home relative to sexuality. Therefore, parents' own feelings again are extremely important. (6) It should be recognized that it is possible to discuss or teach about sexuality in a matter of fact way just as one teaches children about other routine things. Some parents express concern about their ability to do this kind of teaching with their own children. However, in the course of their observing their child discussing issues of sexuality without becoming unduly upset or stimulated, they gain a new awareness that it might be possible for them to continue such discussions at home. Before leaving the general issues of parental reactions to the sexual development of their children, one important additional point needs to be made. I feel that parents, teachers, and others working with the handicapped individual have a very important responsibility. That responsibility is to provide the handicapped person with as much of the kind, quantity and quality of sexual information as that person can assimilate at his developmental level. It is critically important to provide as much opportunity for the handicapped person as

possible so that he/she may later participate in decisions that will affect his or her life and future happiness. I consider this statement as the basic rationale for encouraging sex education for the developmentally handicapped person.

As noted above, one can probably safely assume that the multi-handicapped child probably experiences the normal sexual impulses and feelings that any other individual experiences. Most of the literature suggests that individuals functioning at or above the level of moderate mental retardation may be expected to have such normal feelings. Chess, Korn and Fernandez (1971) [4] have indicated that a fairly high proportion of the Rubella Syndrome children fall at or above the level of moderate mental retardation. Therefore, these children will probably experience and show sexual behaviors such as self-exploration, exploration of others' bodies, masturbation, breast development, menstruation at the normal time, and other signs of body growth and development. In the deaf-blind child we can certainly assume that certain normal needs and developmental expectations exist. The deaf-blind infant has a particular need for physical closeness and for skin-to-skin touching. He needs to explore others' bodies particularly the face and the mouth in order to begin to gain some awareness of his own body. A basic principle that is involved is that of the child's learning to differentiate himself from others and from the rest of the world simply by learning that other objects (people) exist outside himself. The deaf-blind infant will very early begin to explore his own body, to manipulate his genitals and eventually to begin some early form of masturbation much as the normally developing infant does. It is particularly important with the deaf-blind child to help him move on from these early preoccupations to exploration of other aspects of himself and his environment. It is important for this child to eventually learn control of his bowel and bladder. It is important that he learn control of other bodily capabilities such as hitting, biting, and scratching himself or others. All of these tasks are seen as important preliminaries to the child

beginning to differentiate himself from another in a sexual sense.

The important question with the deaf-blind child relative to sex education as well as to any other kind of teaching endeavor is to determine whether and to what degree the child is able to receive stimuli or to communicate in any way. The major questions that need to be asked are how able the child is to communicate anything, to determine what residual vision the child has in hopes that it might allow the use of pictures and possibly some signs; to determine what residual hearing the child has to allow use of some verbal labels, and to determine how able the child is to be brought out of a withdrawn state. Unless the child has some capabilities in one or other of these areas, issues of sexuality may be quite completely inaccessible. The child who has little, if any, sensory or communication channels open to him will probably resort to self-stimulation including masturbation and this might well be considered an understandable adaptation.

The practical suggestions one can make relative to helping the deaf-blind child with learning something about his sexuality are probably quite similar to suggestions that would be followed in teaching this multi-handicapped youngster anything. Certainly, in early infancy, when there is a great deal of touching and other tactile stimulation the child is learning much about his body. During feeding, changing diapers, bathing, cuddling, toileting, a great deal of touching occurs in which the child learns about the contours and abilities of his own body. The natural direction is to allow the child to experience the fact that in many ways his body is similar to others which he can confirm by touching the body of another. It is important to let the child explore a variety of textures, materials, positions, and actions. These self-experiences can then be contrasted with the touching and experiencing of other people, animals, playthings, in order to constantly build on distinctions between animate and inanimate objects. It is important to help the child build a concept of personness in order that he may learn soemthing about objects which will reciprocate his advances from those that will not.

When the child has become more familiar with people and is capable of relating to those individuals who are regularly around him, it may be possible to begin making some fine distinctions and discriminations that may help him discriminate male from female. Touching of the hair and noting length of hair, touching child's hand to mother's breast versus father's chest may be other ways of conveying the distinction between the two different kinds of people. In addition, it is important to observe the child's own exploratory efforts and to try to fit them into some form of teaching-learning experience. His touching of the genitals may be an opportunity to convey some kind of label for the genitals. These behaviors in the deaf-blind child may be equivalent to responding to a more verbal child's questions about sexuality. With the sensorially and communication-handicapped child the parent may even more importantly need to help him express himself by picking up on his non-verbal behaviors. A whole range of other techniques might be suggested in the form of the child becoming aware of distinctive clothing that may help dramatize male/female differences. The use of dolls with realistic genitals and/or distinctive clothing may be another approach. Such dolls are becoming more available. Where there is some residual vision, simple and bold line drawings may be the most effective graphic display. The pictures might hopefully be paired with the signs or other verbal symbols. Demonstrating on the child himself or having the child observe parents in some forms of affectionate display again may be helpful particularly when verbal labels are attached if this can be appreciated by the child. Where some residual vision or hearing is available, a greater variety of techniques are possible.

The issue of menstruation is undoubtedly an important one and sometimes a troublesome one for parents of the multiply handicapped child. A variety of visual and pamphlet-type materials are available for the handicapped girl who is sighted. [5]

However, with the deaf-blind girl a much more concrete demonstration -- a modeling approach is required. Strong assurance needs to be given the girl that menstruation does not signal illness or injury. Probably the most effective technique is for the mother to simply demonstrate concretely how the pads and belts are worn and adjusted and disposed of. This frequently requires that the mother be able to overcome reservations that she might have in order to carry out such a demonstration of the mechanics as well as other hygenic behaviors.

Masturbation is probably one of the most common sexual behaviors and yet one of the most troublesome issues for many parents to cope with in their handicapped child. The parent clearly has to come to grips with his or her own feelings and attitudes about masturbation. These often include moral, hygenic, or aesthetic objections, and misconceptions about physical and medical consequences attached to masturbation. It should be recognized that masturbation is a highly acceptable and very normal kind of behavior in handicapped as well as in normally functioning children. With all but the most rare exception it is a totally harmless behavior and provides a kind of sexual release. Punishment and sudden increase in attention to masturbation can make it a highly anxiety-laden activity and can strongly increase its frequency. When the frequency or intensity of masturbation does suddenly increase, it might be in response to some kind of topical irritation of the skin. The most effective approach to masturbation is that of redirecting the child's attention to some other activity if the masturbation occurs in inappropriate places. If it occurs in relative privacy such as in a bathroom or in the child's bed, the best policy would be to ignore it. It is important to make clear to the child where the appropriate place is for masturbation. Some handicapped children resort to masturbation or other self-stimulatory behaviors to such a degree that it excludes all other kinds of activity. When masturbation becomes compulsive and occupies ever increasing amounts of the child's time, an agressive, aversive reinforcement kind of program may need to be undertaken. Techniques for approaching such compulsive or self-injurious behaviors are available in the literature.[6]

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NORMAL AND ABNORMAL REFLEXES
and their
INFLUENCE ON MOTOR BEHAVIOR
Question Outline

By Barbara Evans, R.P.T., Linda Summers, O.T.R.

How does a child learn to move?

1. Random movement-purposeless movement
2. The child begins to observe and feel own movements (plays with own foot or hand).
3. Random movement becomes controlled (child bats at object or noise, he begins to fingerfeel) purposeful movement.

How does a child learn about his environment?

"Learn to move so you can move to learn"
The child learns by exploring himself and surroundings with purposeful movement. (Normal children are into everything or everything goes straight to their mouth or is thrown).

How does development occur?

1. Motor development occurs in an orderly sequence (head turns to mother or sound, child rolls over to reach an object, then he begins to move on his belly, then to all fours, then to standing)
2. Muscle development occurs in three stages.

   a. Mobility - the infant flails arms and legs around without purpose.

   b. Stabilization - the child holds a position but does not move.

   c. Mobility superimposed on stability - the child can move in all fours position or reach for object.

What is a reflex?

Involuntary response.

What are some basic reflexes in development?

These reflexes occur normally as a integral part of development and become pathological only when they dominate motor behavior.

1. Flexor Withdrawal - when the leg or arm pull away from stimulus (when you touch a hot stove or step on a sharp object).
2. Extensor Thrust - arms and legs straighten out, back may arch.
3. Crossed Extension - child's legs cross over or scissor.
4. Asymmetrical Tonic Neck (ATNR) - one arm and leg extend on the same side and the opposite arm and leg flex-this is determined by the head position (Fencing position, tennis serve, golf swing).
5. Startle - With a sudden noise, movement, or touch the child would jump, or move.
6. Tonic Labyrinthine - child on back lies out flat and on his stomach he flexes up in a ball (most people sleep on side curled up and on back straighten out).

7. Protective reaction - when pushed off balance or tripping you put an arm or leg out to catch yourself.

8. Overflow - when one arm or movement takes place something else moves also (sticking your tongue out to help you think).

9. Neck Righting

   a. Total rotation - head turned to side and the body follows over to stomach then up to all fours.

As more control develops:

   b. Partial rotation - head turns and child comes to side using arms to push up to a sitting position.

As more control of movement develops:

   c. Symmetrical - the child is able to come straight up from back lying to an upright posture.

10. Equilibrium reaction - This is the final level when the child is able to keep himself upright by adjusting his center of gravity when balance is threatened.

Many children are able to walk but are very stiff, rigid or fearful of moving from one place to another. They may revert to a lower level of behavior to protect themselves.

Why walk when crawling is so stable?

Why talk when everyone waits on you before you even ask-all you have to do is grunt or point?

Why feed yourself when someone is always right there to do it for you?

Can we affect the childs development by influencing his environment?

We can structure his environment by placing him in a particular reflex or position to enhance movement. We can give him a structured and consistant environment in which he can work and live.

Do not let a diagnosis of a child affect your expectations of the child.

A program for multiply handicapped children must encompass their total needs. It must provide for as much normalization as possible, and must be flexible enough to adapt to each individual child's needs.

To be able to provide a therapeutic environment for the child, individual evaluation must be made. Some of the things to observe would be as follows:

1. What level of self care skills has he achieved, including feeding, dressing, grooming and toileting?

2. Muscle tone: too much, too little; poor control; awkward etc.?

3. Developmental level: does he have good head control, can he roll, sit, crawl, stand etc.? How does he move around?

4. Does he have any musclo-skeletal deformities?
5. What sensory systems are intact and where are there deficits?
6. Does the child have any favored position?
7. How does the child communicate, or can he?
8. Are there any behavior problems, such as self destructive behavior?
9. How does the child play?
10. Does the child have difficulty with fine motor coordination? Why?

The care of the child must be a united effort of the family, educators, therapist, medical staff and others to provide the environment necessary for learning.

NORMAL AND ABNORMAL REFLEXES
and their
INFLUENCE ON MOTOR BEHAVIOR

By
Barbara Evans, R.P.T., & Linda Summers, O.T.R.

The presentation on "Normal and Abnormal Reflexes and their Influence on Motor Behavior" was to show how development occurs in an orderly sequence. The Multiply Handicapped child often times becomes delayed in development. Developmental therapy follows an orderly sequence of learning and the objective of our presentation was to show how therapy can stimulate higher levels of development.

HOW DOES A CHILD MOVE?

1. An infant first learns to move through random movement. At this level the infant has not yet gained control over this arms and legs and they move randomly. The movements have no apparent purpose for the infant.
2. The child next begins to observe and feel his own movements. He becomes aware of his toes, arms, legs, etc.
3. Next the child discovers he can control movement of his arms, legs, toes, etc., and he can exercise his control continuously by practicing and repeating his movements, for example; continually mouthing objects. At this level the child's movements have become purposeful.

He is now able to explore his environment and organize time and space.

HOW DOES A CHILD LEARN ABOUT HIS ENVIRONMENT?

The statement that a child "learns to move" and then "moves to learn" is very important when working with the multiply handicapped child. A child learns his capacity for movement and explores his surroundings with purposeful movements. A child may repeat an activity such as placing an object or fingers in mouth, knocking objects over, or throwing objects until he masters control of his extremities. A child will also "practice" skills in development. The child will roll over by accident, then he will realize he can initiate the movement and continue to roll all the way over.

He may then see an object he wants and roll to it or start to crawl. A normal child needs motivation to develop to a higher level. He will see an object (toy or person) and reach for the object. As the control of his body is improved the child will begin to use higher modes of locomotion.

A multiply handicapped child may plateau on a particular level for example; the rolling level, because he can not coordinate his body to support his weight on his hands and knees. This is where developmental therapy plays a very important role in realizing what is preventing the child from going to a higher level of development. The child now has mastered control of his movements and begins to move to learn about his environment.

HOW DOES DEVELOPMENT OCCUR?

There are a number of systems developing simultaneously as the child grows and matures. During our presentation we discussed two of the systems.

1. Muscle development occurs in three stages.
   a. Mobility - The first stage is when the child shows random movement. His arms and legs flail around without control or purpose.
   b. Stabilization - The child next holds a particular position and does not move. For example; when a child on his belly raises up on his forearms or hands to look around but does not move.
   c. Mobility superimposed on stability - This is the stage when a child starts to move. He will begin to crawl by holding one extremity on the ground; then he lifts and moves forward with the opposite extremity.
2. Motor development occurs in many stages. A child will first turn his head to a stimulus, such as being breast-fed, and then will hold his head by himself while on his belly to look around. He will progress through rolling, belly crawling, crawling on all fours, sitting, kneeling, walking and standing.

The developmental approach to treatment follows the same sequence.

Many of the above stages may occur simultaneously, such as rolling and crawling. A child does not need to crawl before he can walk. It is important to know, for example; good head and trunk control are necessary to crawl, sit our stand. During each stage a child learns much more than the task per se.

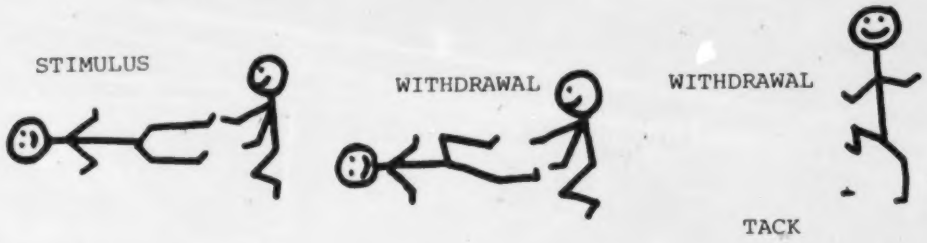
WHAT IS A REFLEX?

A reflex is any involuntary response.

WHAT ARE SOME BASIC REFLEXES IN DEVELOPMENT?

The reflexes we discussed occur normally as an integral part of development and become pathological only when they dominate motor behavior beyond a certain age. We as adults maintain many of these reflexes but we are not dominated by these movements. We have cortical control over these movements and can maintain our balance and posture. For example; when we touch a hot object and pull away we return to our previous posture. We accomodate for the movement which a child dominated by a reflex can not do.

1. Flexor Withdrawal - When the leg or arm pulls away from a tactile stimulus into a fetal position. This is still evident in older children and adults when they touch a hot stove. You will pull arms or legs away from the stimulus, toward your body, but you have control to return to your original position after the response.



2. Extensor Trust - When the child shows extension of the head, arms, legs, and may show arching of the back. We show this when we stand but we control the amount of extension needed.

BACK ARCHES

ARM & LEGS EXTEND

3. Crossed Extension - When the legs cross over each other when stimulated. This is most evident in Cerebral Palsy children in their scissoring gait.

LEGS CROSS

4. Asymmetrical Tonic Neck (ASTN) - This appears when a child turns his head to the side. The face side will extend and the skull side will flex. This occurs both in arms and legs. This is evident when we fence, play tennis or golf.

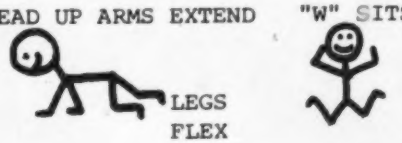
SKULL SIDE - FLEX

FACE SIDE - EXTENDS

5. Symmetrical Tonic Neck -

a. When the head is held up the arms extend and the legs flex. Many children show this reflex when crawling. They will "bunny hop" which is placing extended arms down and hopping both flexed legs to arms. Many children who show this reflex will "w" sit.

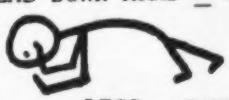
HEAD UP ARMS EXTEND "W" SITS



LEGS FLEX

b. When the head is flexed down the arm will flex up and the legs will extend which makes it hard to maintain a crawl position.

HEAD DOWN ARMS _ FLEX



LEGS - EXTEND

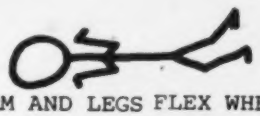
6. Startle - When a sudden noise, movement, or touch causes the child to jump, move, or loose balance. We retain a startle throughout life but are able to control our bodies after the startle to return to correct posture. A child with a severe startle has great problems with balance. The arms will raise up in startle position and he will not be able to reach down with his arms to catch himself.

7. Tonic Labyrinthine

   a. Supine - When the child is lying on his back his arms and legs extended.

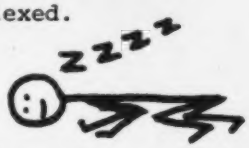
ARM AND LEGS EXTEND WHEN ON BACK

   b. Prone - When the child is lying on his stomach, his arms and legs are flexed up under his trunk.



ARM AND LEGS FLEX WHEN ON STOMACH

   This is evident when we sleep. On our back we extend our legs and when side lying we are flexed.



8. Associated Reactions (overflow) - When one arm moves or movement takes place something else moves also. For example; when you are feeding your child you may be moving your mouth as your child moves his. We can control our overflow and stop when we become aware of what we may be doing.

9. Protective Extensor Thrust - When the child is tipped forward he will automatically extend his arms forward to protect himself. This should remain throughout life and becomes abnormal when it does not appear.

10. Neck Righting - When a child's head is turned to the side the body will turn to the same side. This will help when the child starts to roll over. It happens first by accident and then the child will gain control over this movement. This leads to three stages of coming to standing;
    a. Total Rotation - The child will turn his head and the body follows to stomach. The child will then go to all fours and then to standing.
    b. Partial Rotation - The child will turn head and then body comes to side using arms to push up to a sitting position then to standing.
    c. Symmetrical - The child is able to come to standing from lying on back by sitting straight up and then stand up.

An interesting way to observe this is to ask a child and/or adult to lay on the floor and then stand up.

11. Equilibrium Reactions - This is the highest level of development -- when the child is able to keep himself up right by adjusting his center of gravity when balance is threatened. When the child is pushed to the right side, for example; the left arm and leg will abduct (away from body) and the right arm and leg will extend toward ground on floor.

A movie was presented to demonstrate those reflexes as they occur in normal development and how they often become delayed and influence motor behavior of multiply handicapped children.

Prescribing therapy and working with the multiply handicapped child is a many faceted task. Each child, with his own unique assets and his own disrupting handicaps, must be individually evaluated. It would be impossible to provide an explanation of different techniques for each specific problem. However, understanding developmental principles and appreciating their influence on learning, will help in drawing up some general principles of care; and aid in understanding some of the barriers to learning and movement in the multiply handicapped child.

A program for multiply handicapped children must encompass their total needs. It must provide for as much normalization as possible, and must be flexible enough to adapt to each individual child's needs. The first step in providing a therapeutic environment for the child which would facilitate development and learning is a thorough evaluation of the child.

There are numerous developmental scales available for the purpose of evaluating the child. However, for our intent, it will only be necessary to describe some of the things essential to observe without mentioning any formal scales. Assessments often times fall short of accurately describing the child because they are done in a contrived situation. For this reason, observation of spontaneous behavior of those children is also essential, together with parents' reports.

What level of self-care has the child achieved? In the area of self-feeding, we can provide an example of the importance of careful observation in understanding the barriers to development and providing subsequent care. A child may refuse all textured food. His reaction may be volatile, throwing spoon, bowl and everything else in his immediate vicinity and then turning around and biting the aide or even himself. On the other hand, he may react with a simple tongue protrusion, in which all the food may come out or somehow, selectively, only the textured particles. There are a number of possibilities to explain the different behavior. Take a child who has possibly been institutionalized and because of the difficulty in feeding him, attendant staff for reasons of efficiency and providing adequate nutrition, osterize his food and put it in a bottle. As long as a child is on a bottle with no other method of feeding attempted, he will never learn tongue mobility, which is an essential process in chewing. (Try moving food between your teeth next time you are eating without using your tongue). In the normal process of learning to eat, a child learns to adapt gradually to textures, temperatures and tastes. This process occurs concurrently as he develops the tongue mobility, jaw and lip control and desensitizes gag and bite reflexes, all basic to the normal feeding process as well as being a precursor to speech. The point I want to make is that many of our children are deprived of this opportunity and, therefore, have lacked the stimulation to develop normal oral mechanisms essential for eating and speech.

Tongue protrusion may be a reflex; the child may have no control over it. In this case, specific therapy to inhibit this protrusion and facilitate some normal tongue movements would be necessary. Many of these children display excellent tongue mobility by selecting only those foods they do not like and then spitting them out. Again, some of those may still have hyperactive gag reflexes or even malocclusion, making them unable to chew. There are also those children who never feed themselves because there is always someone right there to do it for them, including

osterizing it for them so they do not have to chew. The problem must be defined before any program should be attempted.

Feeding is only one component of self-care. Grooming, toileting and dressing are also considered. I think this is basic for even the most severely physically involved child. Whereas a goal of dressing may be unrealistic, most of those children can at least assist, or at best not resist, a dressing program. Besides, much learning can occur during the routine process of dressing. A child can receive tactile stimulation, range of motion, and learn about body parts while concurrently being dressed with little extra effort.

Another important aspect to observe in the child is his muscle tone. If the child has cerebral palsy the difficulty with movements is going to probably be more obvious. And yet there are many subtile cases of muscle dysfunction, some of which may be pathological while others again may be due to lack of opportunity for normal growth and development. As was discussed earlier, muscles, too, develop in an orderly sequence. Awkward movements in a child may be due to lack of co-contraction, which is the stabilizing force allowing us to bear our weight and upon which coordination develops. A normal child spends five or six years developing strength and skill. He is constantly moving; initially learning how to move, then exploring his environment and in play. In contrast, compare the experiences and movement of the normal child with how much opportunity a multiply handicapped child has. Unless we help in providing some of those experiences, those children may never achieve their potential.

How does the child move around? Is he capable of getting around? What is the method of locomotion? Some of the children, because of physical involvement, may not yet be able to move, or even hold up their heads. They may be so dominated by lower level reflexes they have not developed any voluntary movement. Here, again, it is essential to analyze the quality of movement, or lack of it, and determine what is influencing the child's mobility. Many of these children also seem to plateau

at certain levels. For example; some of these children may prefer hitching as their primary form of locomotion and resist efforts to teach them to walk. Why not? Look at the security it provides them, five points touching the ground and if he does run into something it will probably be with his legs, which is easier to bear than having his head banged! Some of these children are extremely adept and swift "hitchers", and it becomes for them an extremely functional mode of locomotion.

Other areas to observe in the assessment of the child are: does he have any musculo-skeletal deformities; does he have any favored position; does he have difficulty with fine motor coordination? Then one must ask why, and how they will influence his behavior, and can they be remediated?

By observing spontaneous behavior one will be able to see how the child manipulates his environment. If there are sensory deficits one can observe what sensory systems are intact, and then capitalize on those when providing stimulation as well as enhance those systems not being utilized. One can tell how a child communicates, to a parent and to a stranger. And possibly what reasons there may be for lack of verbal communication: Is it a problem of oral mechanisms, or is it a withdrawal? One problem frequently encountered in an institution is that a child does not need to talk; why talk when everyone waits on you before you ask, all you have to do is grunt or point?

To reiterate, it must be the "total" child that is evaluated. In just the areas mentioned above, it becomes obvious there must be many people involved in contributing to the assessment of the child. And the continued care for optimal growth in the child will be a result of the united effort of the different professionals with parents, and most importantly with the child.

In the presentation in Wyoming, slides were shown demonstrating therapy utilizing the developmental principles thus far discussed. The question we proposed was:

Barbara Evans, R.P.T., & Linda Summers, O.T.R.

"Can we affect the child's development by influencing his environment?" When developmental therapy, as carried out by the occupational and physical therapy departments, was first introduced at the Training School, we encountered some resistance. Until recently it seems people have allowed the child's initial diagnosis to affect his prognosis. In other words, if a child was severely retarded and physically handicapped, there just was not much hope of him ever learning anything or becoming in any way self-sufficient. He was left in a crib with virtually no appropriate stimulation. Custodial care was provided, he was fed, bathed and his diapers were changed regularly. Consequently, we now have a certain population of residents, deformed, incapable of any level of self-care, some still being bottle-fed or at least spoon-fed osterized food; non-responsive.

In the two years developmental therapy has been operating, we have seen great progress in the children and even some changes in attitudes (probably the greatest achievement of all). We have seen children who had been tube-fed learn to eat regular food and feed themselves; children who initially lacked head control develop through normal stages and begin to walk; children very physically involved learn to sit up in wheelchairs and propel themselves. And perhaps the most rewarding sight of all is to see a group of children, formerly crib-ridden and capable of only the most limited stereo-typed movement patterns, moving around on the floor, playing with toys, and even among themselves, and laughing.

It wouldn't be feasible to describe actual treatment since as has been stated, it is so individualized. However, through our slides we demonstrated some techniques and general principles of stimulation, again, keeping in mind we are working with the total child. Some of the different areas of our programming we discussed were: sensory motor therapy and relaxation, pre-speech therapy, self-care and daily activities of living and development of communication skills.

It is also pertinent to mention we work with extremely low level children developmentally. They would be classified in the sensory-motor period of development (the first two years of life). Most of the children are severely physically involved because of cerebral palsy. Care of these children begin at the very lowest level of inhibiting dominating primitive reflexes and facilitating higher levels of functioning. A thorough discussion of this neurodevelopmental approach would at this time be inappropriate. However, suffice it to say, it too is based on the developmental principles we have already discussed.

Overall, the objective of sensory motor therapy is helping the child learn about his body and control of its movements. This is done in a developmental sequence and involves influencing both sensory input and motor output, with attention also to the "feedback" the child receives from his subsequent movements. This is an adaptive process where the child learns to process sensory input whether it be tactile, proprioceptive (position sense), kinesthestic (movement sense), visual, auditory, etc., and responds with an appropriate motor response. It becomes quite an art sometimes to know the quality, quantity and type of sensory input to provide in order to elicit the correct accomodating motor response. For example; in the process of gross motor development, a child first learns head control while on his stomach, then develops rolling, sitting, crawling, etc.

Relaxation is one component of sensory motor therapy. The initial slides demonstrated different methods used to acheive relaxation. There are many reasons why we set relaxation as our goal. Many of our children are spastic, i.e., the muscles are resistant to movement. Therefore, we must relax these muscles and give the child the opportunity to know the "feeling" (kinesthesia) of normal movement. When some children get excited they react with a total overall reflexive movement of their bodies; they must learn to isolate and refine movement. In order to do this their entire bodies must learn to "let go" and then begin slowly moving one

extremity at a time, again being able to focus attention on just the movement he wants.

The initial slides demonstrated different methods used to achieve relaxation. These methods included: slow, rhythmic swinging in a tire swing; rocking back and forth while laying on stomach on a large inflated beach ball; massage and swimming. Swimming was done in a therapy pool with a water temperature of about 98°F. This has been an excellent medium for achieving relaxation. There are additional benefits in that movement in water enhances feedback information as it increases resistance to movement. The buoyancy of water will also decrease the amount of weight born by long bones, so that when working on preambulation skills, bones that may not be fully developed or that may be weakened from malnutrition or drugs can gradually assume weight-bearing and not have to assume the stress of the total body weight. One drawback to the water is the rebound effect of muscles. This can be illustrated by a child who, when coming out of the warm water begins to chill and the relaxing effect of the water may be lost. However, in most cases we feel the overall gains, the relaxation, and the purposeful movement achieved in the water override this setback.

It is important to emphasize, too, the objective of relaxation is usually not relaxation per se. It is only the background upon which we want to teach the child about his body parts, how they move and how he can move them.

In working with each child it is important to set realistic goals. It may be, because of severe physical handicaps, walking may not be a realistic goal. If we continually expect a child to walk he may meet with nothing but frustration. It may be necessary to even assist him in maintaining an upright sitting posture. But, by doing so we may provide enough stabilization so that he can then focus his attention and energies into feeding himself or learning to propel himself in a wheelchair. It is far easier on the child to assign objectives with which he can succeed and move on as he does so, than continually meeting with frustration

and failure at being unable to achieve "our" expectations. On the same hand, we must not allow ourselves to become content with the level the child has achieved. We had worked with one little girl who had been tube-fed for years and had finally succeeded in getting her to eat regular food. Content with her achievement, we continued feeding her for some months until one day her feeder became distracted, the little girl became quite impatient and reached out, put her feeder's hand on the spoon and moved it to the bowl. Needless to say she has fed h self from then on.

We must also be sensitive to the child's reaction to our stimulation. He will most likely let us know when he is frightened, and we must be alert to his cues. A child we are working with on walking may be walking very stiff-legged and rigid because he has not developed adequate balance and protective reactions, or he may lack the visual cues that we so heavily rely on. It is then our responsibility to help develop those balance reactions of substitute through another sensory pathway than the impaired one. Telling the child everything is all right is not always adequate; he is going to have to internalize that feeling of security.

To continue to describe different techniques for self-care activities, sensory motor therapy or enhancing communication skills would be superfluous for this presentation. The importance of incorporating an understanding of developmental principles with the careful observation of the individual child, and then providing stimulation conducive to the learning of functional skills has been the main theme in our presentation. It is a system aimed at meeting the total needs of the child and requiring the cooperation of the child, family, educators, therapists, medical personnel and all others in any way involved with the multiply handicapped child.

YOUR CHILD GROWS AND DEVELOPS
THROUGH PLAY

by Susan Smith

Some basic things to think about when selecting toys for your child:

1. Does the toy encourage creative play?

   a. Can the toy be used in more than one way?
   b. Does the toy appeal to the senses of sight, hearing and touch?
   c. If the toy does everything itself there is nothing for the child to do.

2. Is the toy appropriate?

   a. Try to see that the toy is neither to hard nor to simple for your child.
   b. Is the toy geared toward your child's interests?

3. Is the toy safe?

   a. There should be no sharp edges.
   b. Painted surfaces should be non-toxic.
   c. Watch out for small removable parts.
   d. Consider what happens if the toy is put into the mouth.

You can help your child's interest in playtime by:

1. Providing a shelf that is easily reached for his toys.

2. Seeing that the toys are a variety of shapes, textures, sizes, weights and colors.

3. Showing, if necessary, how to use a toy. Play with your child, but not for him.

4. Having only a few toys available at a time.

PLAY FUN ON A BUDGET

Recycle, junk is great, be creative

INFANT	TODDLER/PRESCHOOL	ELEMENTARY	ADOLESCENT
Mobiles Noise Maker Bean Bags Measuring Cups Measuring Spoons Jar Lids Plastic salt shakers Plastic lids (different and colors) Wooden Spoons Wash Cloth Sponge Knitted ball	Measuring cups and spoons Plastic margarine bowls Spool Necklace Milk carton blocks Small boxes Cans (graduated sized) Pots and pans (for kitchen band) Magazine picture book Old purse with handles Cardboard boxes Old wind-up clock Any type balls A string and can telephone Coffee can with plastic lid (cut square in lid to push things through) Art Materials Dress-up clothes and hats Sand and water (outside) Cuddly toy (could be made from old wash cloth) Clothes pins Puppets	Ring toss (tape stiff rope into ring shapes to throw over non-pointed pegs) Sewing cards Cans for bowling Paste picture on cardboard to cut up to make a puzzle Hammer, nails, and scrap lumber Inexpensive portable radio Make an adventure book Jump rope Things for playing house Art Materials Small set of garden tools Nuts and bolts *Tire swing *Scooter board (These can be used at other levels - fun for all ages)	Carpentry set Sewing materials Books Musical Instrument Record Player Art materials A tree to climb Balls (basket ball, baseball, football) Typewriter Old auto parts and wrenches Clay Leather Model pits Camera Most of these can be expensive, but check out swap meets, thrift shops, ask relatives and neighbors and if possible have your adolescent pay for some of his materials.

THESE GROUPINGS ARE ONLY GUIDELINES. TRY TO PRESENT TOYS AT YOUR CHILD'S DEVELOPMENTAL LEVEL.

LEGAL RIGHTS OF THE HANDICAPPED (SUMMARY)

by

Steven L. Zimmerman

A range of constitutional rights for handicapped children and their parents is emerging at law. Initially, there is question of whether or not the seriously handicapped child may obtain a life-saving operation shortly after birth contrary to the desires of his parents. Lower Courts in several cases have stated that we must preserve life initially and deal with the quality of life subsequently.

In regard to education, Courts have seriously questioned the validity of the standard I.Q. test and in some cases have deemed it invalid as a sole criterion for placement into special education classes. The law in Colorado suggests that all children of school age may be educated through the public school system regardless of the severity of handicap. This Handicapped Children's Education Act is to be fully implemented on July 1, 1975 and every school district in the State is a participating unit for education of handicapped children. The term "handicap" is broadly defined so as to include almost all children who cannot be accommodated through regular classroom instruction.

In regard to institutions, Federal Courts have decisively acted to interfere with State governments to ensure appropriate conditions. "Right to treatment" lawsuits have been brought in other states which guarantee minimum constitutional rights of dignity, decency, and programs of individualized training for maximum development. The Supreme Court of the United States will soon deal with the issue of whether or not there is a Federal constitutional right to treatment which may be enforced upon the States.

In the area of zoning, Courts have tended to foster the establishment of group homes for handicapped children in all neighborhoods regardless of local zoning and building ordinances. There are cases, however, which do uphold the right of local zoning to control.

In the areas of discrimination against the handicapped, State and Federal statutes have been passed to prevent discrimination in employment against otherwise qualified individuals by reason of handicap alone.

In the area of criminal law, Courts have disallowed civil commitments for indeterminate lengths to institutions for the mentally retarded and mentally ill. Due process is being required and adequate periodic evaluations are necessary to determine whether or not continued placement is appropriate. The new Mental Health Act will ensure basic civil rights to the mentally ill and will be effective July 1, 1975.

In the area of public assistance, benefits to handicapped individuals may be obtained through Supplemental Security Income, a program administered by the Federal Social Security Administration. Methods of estate planning have been devised to allow for moderate sums of money to be held in trust for the benefit of handicapped individuals in addition to public assistance benefits.

The 1970's are the era of litigation, and more attorneys are turning their attention to advocating the rights of handicapped individuals throughout the nation.

HEALTH, LIFE & HOSPITAL INSURANCE

AS IT RELATES TO FAMILIES OF DEAF-BLIND CHILDREN

BY

J.O. Bud Wigen

The topic of my discussion with you is shown on the program as "Health, Life, and Hospital Insurance as it relates to families of deaf-blind children".

Perhaps as an introduction I should review some of the basics of insurance. These basics apply to all types of insurance such as fire, windstorm, automobile, life or health, etc.

What is insurance? Insurance is nothing more than spreading the risk of individuals among the many. I suppose you might compare total insurance to pure socialism -- you have spread the risk over the total population at one uniform price. But, we are as yet living in a society which rewards individuals for their own resourcefulness, their own acievement, their good health, their carefulness, their ability to accept their own responsibility and, yea, even those blessed with fortune. This same principle carries over into insurance whereby those that maintain a low loss record, or are classified in a good risk category, usually because of their own doing, have a lower rate for insurance.

For example, a middle aged, happily married man with no young drivers, and with an accident free record and no physical or health defects has a very low rate for auto insurance. The business man in a non-hazardous occupation with a fireproof building equipped with sprinklers situated in an uncrowded area and near a fire station manned by competent firemen with adequate and updated equipment, and who maintains first rate equipment and cleanliness has a very low fire rate. The young male driver with a record of convictions and accidents may be unable to purchase auto insurance or if it is available, at an extremely high rate. The single male under 25, even without any violations or accidents

finds himself in a high risk category. You parents with teenage drivers are aware of this. Experience indicates that a single male driver under 25 years of age has better than a 50% chance of being involved in an accident. Anticipated claims, based on past experience, dictates the rate charged for insurance. Simply stated, sufficient premium income must be developed to pay for anticipated claims plus cost of administration.

What I am trying to say is that the greater the hazard, the higher the rate and that there is a point where it is economically unsound to provide insurance coverage at all. The point is reached where it is impossible to spread the risk among enough people or the cost to those is not economically feasible. A good example of this is the crisis in medical malpractice in many areas of the country today.

We now get down to your specific situation.

First, statistics for the deaf-blind are not credible. The brochure entitled "Services for Deaf-Blind Children in North Dakota" states "before the 1965 rubella epidemic, there were only a few hundred deaf-blind children in the United States". Now there are 5,000. In other words, there is not enough experience for positive decisions as to rating. There is, however, enough experience in the blind-only area to draw some conclusions.

Usual life insurance practice for those who are blind totally is to assess $4 to $5 extra per $1,000 of insurance and decline all accident insurance. (The standard rate may be $20.00 per thousand). Blind children are even more hazardous and may be charged $5.00 to $7.50 extra. Generally, there are limitations as to waiver of premimum and double indemnity (for accident) coverage.

J.O. Bud Wigen

We contacted Provident Life Insurance Company whose headquarters is in Bismarck and reviewed the situation with their chief underwriter. Provident, as is the case with all companies, bases their underwriting to a great degree on what their reinsurers position may be. We checked two of Provident's reinsurers policy position in regard to deaf and blind. Both reinsurers would not accept children in this category under age 15 principally because of the high accident frequency. After age 15, all cases would be examined and a determination made on the basis of the merits of the individual case. A well adjusted individual could possible be written at standard rates or at a slightly additional surcharge of $2.50 per thousand. As to the amount of insurance available, the insurable interest and the need factor would govern. As an example, a single individual dependent on others for support, would have little need for a large amount of life insurance.

Because of the high risk factor of deaf-blind children, particulary those that suffer from additional physical handicaps, the availability of life insurance is just not present on an individual basis.

There is some difference on a group basis, and a family plan policy which may or may not afford some coverage for the spouse and dependent children. It is possible that a waiting period may be involved in which case the insurance company could rider out death caused by existing defects. It is also possible that coverage could be obtained to cover immediately upon birth in which case pre-existing conditions may not be excluded. Generally, the larger the group, the broader the coverage in respect to pre-existing conditions and waiting periods.

The situation regarding health insurance is somewhat similar. Individual companies will have varying policies. The possibility of obtaining health insurance on an individual basis for deaf-blind children is quite remote for those who make application after the birth of the children; however, you have lost nothing by making inquiry of various insurance agents. We contacted Blue Cross of North Dakota

and were advised that they would consider each case on an individual basis in a bank depositors' group classification. Here again, on a group basis, the chances of obtaining coverage improves as the size of the group increases. This goes back to the basic idea of spreading the risk.

The picture brightens considerably for the parents of a child born into an existing group or family plan. Here again, one must check for waiting periods and pre-existing conditions exclusions. North Dakota has approximately 350 companies licensed to sell accident and health insurance. Although the policy forms are somewhat uniform, the form can vary from one company to another. Since more than 50% of the people in North Dakota are members of Blue Cross, Blue Shield, I will quote pertinent portions of their normal group policy.

The term "member" shall mean the subscriber, and the subscriber's spouse when physically residing with the subscriber, and each of their unmarried children under the age of 22 years when physically residing with the subscriber (except while attending school) in a normal family relationship, except that a child shall be considered under age of 22 years until the end of the year in which the child becomes 22 years of age."

Under maternity benefits "C", a member shall be entitled to coverage as a newborn child from birth for any illness, accident, deformity, or congenital condition, even though the mother is not eligible for coverage. For routine nursery care as a new born child, the mother must be eligible for maternity benefits. A member is entitled to maternity benefits after a waiting period of 270 days of continual membership under a family contract.

Article VII - Waiting periods.

Hospital services for any condition, previously treated or diagnosed by a physician, which condition existed before the effective date of this contract, or for tonsillectomies, adenoidectomies, treatment of hernias, hemorrhoids or cholelithiasis

(gallstones) will be provided only after this, or a prior Blue Cross contract has been in effect for 270 consecutive days immediately preceeding the member's admission to the Hospital.

What this means is that if coverage is accepted for the family, the normal benefits under the contract will be paid for any pre-existing condition after a waiting period of 270 consecutive days.

Some companies will rider-out specific illnesses or physical defects and benefits are never provided for claims associated with those named exceptions unless the rider is removed by the company. Blue Cross of North Dakota does not rider-out coverages, but may decline the risk all together.

I am concerned that I have not been a messenger of good tidings to you, and for that I am sorry. My parting suggestion to you is to shop around for insurance the same as you might for clothes, a car, or what have you. Most important - contact a good reliable insurance agent - someone that you can trust. I have often times compared buying insurance to buying a diamond. In shopping for a diamond, you would not search the side streets and back alleys for a bargain - you would go to someone that you know is reliable - one that you can trust. The same applies to insurance -- if you do not know insurance, know your insurance man.

I am not a specialist in health and life insurance, but I would be happy to try to answer any questions. Thank you.